



GIFT of LIFE
Family House

www.GiftOfLifeFamilyHouse.org

UPDATE

CELEBRATING OUR 5-YEAR JOURNEY

The Family House rounds out a 'circle of care' for transplant patients and families

Our 'home away from home' has helped thousands find peace of mind, and hope.



"Where does a polar bear keep his money?" teases 5-year-old Amelia Torgersen to our reception desk staff who have been eagerly awaiting her arrival. "In the snow bank," she answers and giggles.

Every time Amelia comes running into the Gift of Life Family House with her parents, Bonnie and Brian, she immediately looks for the smiling faces she has come to know and trust. She brings her latest stuffed "friend" and asks that it be given a yellow wristband ID, just like hers.

It's hard to believe that bouncy, fun-loving Amelia had a liver transplant just nine months ago, or that she is now undergoing chemotherapy for PTLTD (Post-Transplant Lymphoproliferative Disorder), a complication of her transplant surgery. Amelia has struggled since birth with Alagille syndrome, a rare genetic disorder characterized by abnormalities to the bile ducts that harm the liver and can affect other parts of the body. The genetic defect that causes Alagille can be inherited, or occur randomly.

Amelia had heart and kidney surgeries, even before her liver started to fail. At that point, the Torgersens relocated from their home in Nashville, Tenn. through Brian's employer — first to Florida and then to Pittsburgh. They wanted to be as close as possible to

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continued on Family House page 2

The Children's Hospital of Philadelphia and its renowned Alagille Syndrome Clinical Care Program, and for her transplant surgery.

Not one to complain, Amelia now bravely faces too many "ouchies" during chemotherapy, but looks forward to staying at the Family House where our staff make her feel special.

..... Five years of caring

On July 18th, Gift of Life Family House celebrated its fifth year of serving transplant patients and their families receiving care at one of the eight transplant centers in Greater Philadelphia. In this short time, we have served more than 1,300 transplant families, many of whom have stayed with us several times over the course of their loved one's care. In total, we've provided over 33,000 room nights of comfort.

"At first, we didn't know how long it would take for the community to support the project," says founder and CEO, Howard Nathan, reflecting back on the leap of faith that brought together benefactors, board members, health care providers, government agencies, and other supporters to help build a "house" for patients and families going through the transplant process.

Today, the success of the Family House is evident. "I ask almost every day about occupancy. It makes me proud when 28 out of our 30 rooms are filled. It reminds me that we did the right thing, that the need that's desperately there is being met."

"I think what sets us apart is our staff members who are there, available, and who care 24/7," notes Howard. "I think that families understand that and are touched by it."



Howard M. Nathan, Founder and President, Gift of Life Family House.

The Torgersens agree. When Amelia came to stay at the Family House after her liver transplant in December, she was drawn to the kid-size Adirondack chairs on our patio. But because it was cold and snowy, she couldn't sit outside. When they came to stay in the spring, Amelia's first thought was to run outside to sit in 'her' chair, but the chairs weren't there, explains Brian. "So we go inside to Diana Elbanna (resident manager) and Amelia says, 'Miss Diana, where are the little tiny girl chairs?' And Diana says, 'They're not out there.' So there was this brief commotion over the chairs. The next week, guess what, the little tiny girl chairs were there."

Adds Bonnie, "Even on the days that are difficult for Amelia, she talks about sitting in 'her' chair. And so the patio is somewhere we can go with her at the end of the day where she has a little time to sit in her chair and just relax and refuel for the next day."



Whether it's having access to a fully stocked pantry and tasty leftovers if they miss the evening meal, or toiletries they forgot to pack, the **Family House is a safe and comforting haven** for them. "We don't lack for anything there," says Bonnie.

..... Rounding out a 'circle of care'

A 'circle of care' for transplant patients and families begins when a person with end-stage organ failure is listed for transplant. The list is national and *Gift of Life Donor Program* works with its partners around the country to find willing donor families and viable organs.

"The reality is that the number of people who can donate is very small. Only about 1 to 2 percent of all of the people who pass away can be considered as potential organ donors," explains Howard, who has been with *Gift of Life Donor Program* since 1978 and is its President and CEO. "In our region, out of about 40,000 people who die each year in the 129 hospitals we serve, there are only approximately 800 who could be potential organ donors. That's why there's a shortage. It's not because people are unwilling. It's because the number who are medically suitable is very small.

"This year we'll have close to 500 organ donors and more than 1,300 people receiving transplants in our region. That doesn't sound like a big number, but it's the largest anywhere in the United States, probably the world, for any one region."

Gift of Life Donor Program is responsible for working with the transplant teams to coordinate the donation and recovery of the organs and safely transport them to waiting surgeons, patients, and families. The Family House takes care of families while their loved ones are waiting to be transplanted, during recovery, and throughout post-transplant care. While other transplant houses typically serve one transplant center, the Family House serves all eight centers in its vicinity. "That's pretty unique, and it's extremely gratifying to me," says Howard.

In addition to affordable lodging, home-cooked meals, and transportation, the Family House also provides education, counseling, and emotional support through its *Caregiver Lifeline Program*. The first of its kind, this program provides a supportive network and educational services specifically tailored to the needs of organ transplant patients, family members and caregivers — those staying at the Family House as well as those living in the broader community.

For the Torgersens, the Family House is a "tool in a toolbox" to make life easier. "When you're at that point of fear and anxiety — things that come with the unknown — there's somebody who has got your back. It doesn't make anybody's individual situation better, their difficulties are going to be just as challenging, but to know somebody's got your back is meaningful," explains Brian.

..... Making every day count

When traveling down the long and winding road of caring for a chronically ill loved one, it is easy to lose focus on the everyday things that give life meaning.

"We had to work very hard to give Amelia what we feel is the best quality of life: That is, to step away from the clinical side of things and remember that she's a little girl — and take her to the beach, take her to Disney, take her to the park. Sometimes with the medical side of things, you almost want to put life on hold — until transplant, or until she's done with chemo, or things like that," explains Bonnie.

For Amelia's fifth birthday, at her request, the family went camping. When the weather turned warm, they packed Amelia's medical gear, along with their camping gear, and headed out to Allegheny

National Forest. "Amelia is definitely an outdoor girl," laughs Bonnie. "We gave her a choice of going out on a boat or hiking. She picked hiking. She had a little walking stick. She kept saying, 'I'm the leader, follow the leader.' She loves to explore. She enjoyed studying the rocks, the different leaves, and trees. That's her happy place."

Adds Brian: "She doesn't understand life. As far as she knows, it's kind of rough, because it's always been rough. But she's a fun, loving spirit that when you're around her you just smile. And you don't do it because she said something funny; you do it because she's this sweet, beautiful thing."

Although they have health insurance, the Torgersens have faced substantial out-of-pocket costs since Amelia's birth for medications, medical supplies, formula for her tube feedings, and travel to and from Philadelphia. "By the time you put all of the pieces together, it's a costly process," says Brian.

..... Securing Family House's future

"Each year, we have to raise about \$1.8 million dollars just to keep the doors open," notes Howard. Driving the need for funds is the Family House's commitment to maintaining a low nightly rate of \$40 even though the actual cost for providing all of the included services is \$165 per room per night. Each room accommodates up to four people. Families who can't afford the nightly fee are given subsidies. "We don't turn anyone away because of their inability to pay," adds Howard.

The Family House depends on charitable contributions, large and small, to make this possible. "Last year we had over 2,300 individuals or organizations give us charitable contributions. I wish I could name them all. We've even had grade school kids hold fundraisers and collect money at school. Businesses will do dress-down days and collect \$5 from everybody wearing blue jeans. Those combined gifts of \$200, \$300, they help."

The Family House works," adds Howard, "because of neighbors helping neighbors, whether through charitable contributions or by volunteering."

"Every time I walk through the door at the Family House, it really makes me proud of our team, of the families who are courageous in going through transplantation, and our volunteers. When I meet our Home Cook Heroes — many of whom are transplant families — and our other volunteers, I am truly grateful. We simply couldn't do it without them."

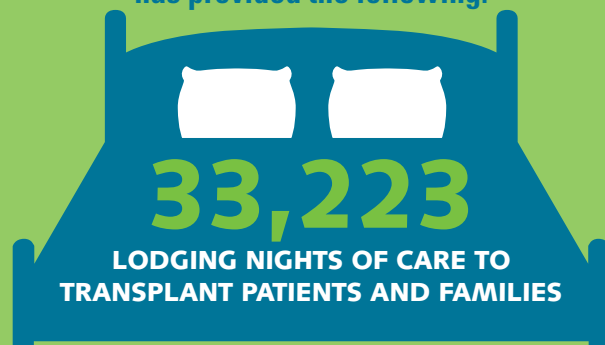
To make a charitable gift to the Family House, or to volunteer, please use the enclosed envelope or visit us online at www.GiftofLifeFamilyHouse.org.



Stay tuned over the next few months as Gift of Life Family House unveils a special way that you, your family and friends can celebrate 5 years of the Family House!

5 Year Stats!

Since July 2011, Gift of Life Family House has provided the following:



TRANSPORTING **11,194** GUESTS
AND DRIVING **45,790** MILES

6 WAYS to Help Support the Family House this Fall



Support the Adopt-A-Family Program

Consider making a tax-deductible gift to the Adopt-A-Family Program – each \$40 contribution helps support one night of lodging for a family staying at the Family House who cannot afford the nightly fee. You can contribute to sponsor one night, two nights, a weekend or more. Gifts of any level are meaningful. To make a charitable gift to the Family House, or to volunteer, please use the enclosed envelope or visit us online at www.GiftofLifeFamilyHouse.org.



Host an Event

From golf outings to intimate dinners in your home, there are countless ways you, your family, and friends can fundraise for the Family House. Fundraising events are also a great way to reconnect with family and friends and remember or celebrate a loved one, while supporting our important mission.



Become a Home Cook Hero

Groups of up to 10 people can provide, prepare (on or off-site) and serve a meal to guests staying at the Family House. Enjoy cooking in our fully equipped kitchen as well as seeing the impact of your service on our families first-hand.



Host a Wish List Drive

Keeping the Family House stocked with basic home necessities – such as food, toiletries, and pantry items – requires a lot of donated items. This is an excellent activity to involve your family, company, religious group, or friends. You can also collect grocery store gift cards to keep our refrigerators stocked with the things we run out of most – milk, eggs and butter! The Family House is also in need of gas cards to keep our free shuttle service operational – transporting patients and families to and from local hospitals each day.



Join the Legacy Society for Planned Giving

By making a “planned gift” – a gift through your estate – you can ensure the future success of Gift of Life Family House and have the satisfaction of knowing that your values will live on through the loving care we provide.



Become a Corporate Partner

Through volunteerism, sponsorships, grants and program support, hundreds of corporations have partnered with Gift of Life Family House to support transplant patients and their families. In return, corporations receive unique recognition, brand visibility through our various communication tools and social media platforms, as well as opportunities for employee team building events and ways to engage and reconnect with clients. If your business or corporation is interested in supporting programs or other initiatives at Gift of Life Family House, we would be happy to help create a mutually beneficial partnership.

For more information, contact Sara Cohen, Development Manager at scohen@giftoflifefamilyhouse.org or 267-546-9812.

FACES OF THE Family House

Meet Luke McGrath



“During a really stressful and hard time for our family, it was a sense of relief knowing that my father had a great place to stay while recovering. I felt that he was always under the best care in a really amazing place.” —Conor McGrath, pictured below with father, Luke, lung transplant recipient and current Family House guest

Celebrating a Second Chance at Life

Luke McGrath worked as a Director of Special Education for 35 years in Somerville, NJ. He planned on retiring in the summer of 2014 to start a new journey of crossing off items on his bucket list with his wife, Sarah. Instead of traveling the world, however, Luke found himself traveling to Philadelphia after being diagnosed quite unexpectedly with nonspecific interstitial pneumonitis in 2013 – a condition that would eventually lead to Luke receiving not one, but two life-saving lung transplants.



After multiple visits with doctors in Philadelphia, Luke was put on the waiting list in September, 2014 to receive a lung transplant. After only eight days on the wait list, Luke miraculously received the call for his gift of life.



Meanwhile, Sarah stayed close to him at Gift of Life Family House, to support Luke through his transplant journey. “It took such a burden off of us that my wife had a place to stay,” explains Luke, who later joined Sarah at the Family House for his recovery.

Luke seemed to be doing quite well after his first lung transplant. Then, in October of 2015, Luke began to experience rejection and had to be hospitalized once more. In early March 2016, the doctors told Luke that he would need to be re-listed for a transplant due to the severity of the rejection.

On May 5th 2016, Luke received the gift of life a second time, this time, a right lung transplant.

Throughout the ups and downs of their transplant journey, the McGrath family has found solace in the loving care that the Family

House provides. Sarah was well cared for while Luke spent many weeks in the hospital – and then he was able to have a “home away from home” to return to for his lengthy recovery. Not only that, but their sons had the opportunity to visit their parents here in Philadelphia as they, too, had a welcoming place to stay.

“When I visited, everyone working there made me feel very welcomed and comfortable. I was able to spend some nice time with my father during his recovery. The meals that were cooked for us at the Family House made it really feel like home and offered such a sense of normalcy that I’m so grateful for.” —Conor McGrath

Now, with his recovery going quite well, Luke is back to planning his bucket list adventures, beginning with a trip to the Pacific Coast. But first, he is happily spending time with his three sons, Conor, Kevin and Sean. He was especially grateful to be well enough to attend his middle son Kevin’s wedding in June. “I wanted to be there for them,” explains Luke.

Thanks to a charitable act by a donor family and the power of organ donation, Luke can continue to be a loving father and husband. And he very much looks forward to finally crossing some items off his bucket list.

LEFT: Luke with his three sons at his son Kevin’s wedding in North Carolina on June 11th; pictured (L-R) : Conor, Luke, Kevin, and Sean. ABOVE RIGHT: Luke with his wife Sarah.



YOUR 40 Hours Challenge is just around the corner!

PLEASE JOIN US THIS #GIVING TUESDAY – 11.29.2016 – to help the hundreds of transplant families who rely on the Family House as their “home away from home.”

It’s so easy to sign up and participate using our Crowdrise fundraising event page!

Last year, 140 volunteers through 45 teams collectively raised more than \$60,695 in just 40 hours to support the Adopt-A-Family Program—a program at the Family House that helps families who cannot afford the \$40 nightly fee. That’s equivalent to more than 1,500 nights of lodging.

Let’s join together to make this year an even bigger success! Prizes will be awarded to the top fundraiser as well as the top fundraising team.

40 Hours for the Family House is a fast-paced & FUN online fundraising challenge that starts at 8am on **#Giving Tuesday, 11.29.2016** — and only lasts 40 hours! **Sign up today** and help us raise crucial funds to continue to provide lodging and supportive services to transplant patients and their families. **#40hrs2016**



Caregiver Lifeline Spotlight

by Julia Stiffman
Gift of Life Family House Social Work Intern

ACHIEVING BALANCE AS A CAREGIVER

Coping with an organ transplant is something that families may encounter at any point in their lives. Taking responsibility for the day to day care of the patient while also having to tend to your usual obligations can be a daunting task, especially if you’re thrown into the role of caregiver rather suddenly. No matter the situation, it is important to maintain a sense of balance in your life, so that you can perform all tasks to the best of your ability.

Listed to the right are three tips for achieving balance in your life as a caregiver (and as an individual).

1. STAY ORGANIZED When you have so many obligations to attend to in any given week, it is easy for some to get overlooked. Planners are a great way to keep track of your schedule so that you never miss a doctor’s visit, bill, a special event or even self-care practices. One can be bought at any drug store and there are several free online planners such as Google Calendar which can send you reminders before an appointment begins.

2. IDENTIFY YOUR NETWORK OF SUPPORT Juggling all the aspects of caregiving on top of your usual responsibilities is no easy task. Keeping a list of names with contact information can help if you need to change around your schedule, have any questions, or feel like you just need someone to talk to. Some names to consider listing: doctors, nurses, and social workers, your employer, insurance contacts, and any close friends, family, and neighbors. Don’t be afraid to ask for help. During the transplant process, some relationships with friends and family may fade out while others become stronger. Learning who you can rely on can come in handy any time you feel overwhelmed or just need a break. Lastly, locating support from others who have been through a similar situation is important. You can find online and in-person support groups on our Caregiver Lifeline webpage on the Family House’s website.

3. TAKE TIME EACH DAY TO PRACTICE SELF-CARE Even taking a few moments to do some deep breaths can be beneficial in helping to cope with stress and in preparing for or unwinding from a hectic day. If you already have a hobby you enjoy, such as journaling, exercising or reading, try to block out a period of time each day to do that (and put it in your calendar). Keeping up with an activity you enjoy can help not just in relieving stress, but also in maintaining your personal identity as a caregiver and as an individual.

For more information about support groups and self-care, please visit the Caregiver Lifeline Program webpage at www.GiftOfLifeFamilyHouse.org or reach out to social worker Talia Giordano at caregiverlifeline@giftoflifefamilyhouse.org



HOME COOK Heroes

The Home Cook Heroes program brings volunteer groups to the Family House to prepare healthy, home-cooked dinners each night along with brunch on weekends. Participating groups include families, schools, businesses, service clubs, sports teams and more.

We are proud to recognize Home Cook Hero volunteer groups from May – July 2016

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Thank you to those who dedicated
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Kenny Kline Foundation
The Patients & Caregivers HUP
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We apologize for any errors
or omissions and ask that you
contact Samantha Oliphant at
soliphant@gifttolifefamilyhouse.org
to report any corrections.

THANK YOU to our volunteers in the community for coordinating fundraising events and Wish List Drives to support the mission of Gift of Life Family House.

Fundraising Events

8th Annual No Shower Happy Hour hosted by the David Nelson Jr. Memorial Fund
10th Annual Bensalem Township Charity Challenge hosted by the Bensalem
Economic Development Corporation
125 Nights Fundraiser Campaign hosted by Kenny Duncan, Squared, &
PB Education Centre Corporation
Anjali Yoga Gratitude Project
Children's Lenten Project 2016 coordinated by Old First Reformed United
Church of Christ
Christmas Trees for a Cause Fundraiser hosted by Lesko's Tree Farm
Community Giving Back Project Bake Sale coordinated by Sara and
Sasha Tuddenham
Designer Bag Bingo hosted by Team Spiers
Dress Down Day coordinated by School Lane Charter School Staff
"Denim Days" hosted by Boyer's Food Markets Store #3580
Doug Wright Memorial Golf Outing
Jackson's 12th Annual Mulligan on Life Golf Outing hosted by Hennion & Walsh
and the Heller Family
Joe Sommer Memorial Benefit hosted by the Lehigh Valley Community Benefit
Smyrna High School Softball Fundraiser in Memory of Donnie Shaner
Team Matt collection benefiting Gift of Life Family House
ThatsCat Twitch Community Charity Stream coordinated by Megan Hildreth

Wish List Drives

Tahisha Anderson
Stacy Arnold
AtlantiCare Business Office
AtlantiCare Paths ERG
Delco PAHCOM Chapter
Danielle Hill
Henry Lane
Mt. Holly Elks #848
The Philadelphia Firebirds
The Regional Hospital of Scranton
SpecialtyUSA, LLC
Mary & Ross Smith
Voya Financial

CrowdRise Online Fundraisers

Bill's 75th Birthday Gift of Life Fundraiser hosted by Jeanille Gatta
Gift of Life Family House For Organ Recipients – In Memory of
Shawn Grenz hosted by Marchelle Grenz-Sickler
In Memory of Donnie Shaner hosted by Kelly Roscoe
In Memory of Gavyn from Team Axiom hosted by Mike Ballas

An online fundraiser is one of the easiest and most effective ways
to help support the Family House. Simply create a personal or
team fundraising page on the Family House's CrowdRise page
and share it with your friends, family and co-workers!
Visit www.GiftOfLifeFamilyHouse.org for more information.

To make a contribution to Gift of Life Family House, please visit www.GiftOfLifeFamilyHouse.org.

The official registration and financial information of Transplant House d/b/a Gift of Life Family House may be obtained from PA Dept. of State by calling toll free 1.800.732.0999. Registration does not imply endorsement.

United Way #48974 | Combined Federal Campaign (CFC) #28458